Report of the Interim Committee on Head Injury

An Examination and Recommendations for Improved Service Delivery

December 15, 1999

Legislative Members of the Interim Committee on Head Injury

December 15, 1999

The Honorable Steve Gaw, Speaker
Missouri House of Representatives
State Capitol, Room 308
Jefferson City, Missouri 65101

Dear Mr. Speaker:

The undersigned members of the House Interim Committee on Head Injury have completed their charge and respectfully submit this report.

Representative Paula J. Carter, Chair

Representative Vicky Riback Wilson

Representative Amber Boykins

Representative Charles Shields

Representative Jewell D.H. Patek

Interim Committee on Head Injury

Missouri state representatives were appointed to the Interim Committee on Head Injury by Steve Gaw, Speaker of the Missouri House of Representatives.

Chaired by Representative Paula J. Carter, the committee was composed of five state representatives who possessed knowledge and experience in the following areas: budgeting and appropriations; health and mental health; children, youth and families; elementary and secondary education and critical issues. Select officials from the Department of Health; Department of Mental Health; Department of Social Services and the Missouri Head Injury Advisory Council accompanied the committee during the public hearings and provided insights on service delivery, referrals and technical assistance for members of the committee and the brain injury community.

The Interim Committee on Head Injury held four public hearings in the following locations:

October 18, 1999 Kansas City - Kansas City Regional Center

October 19, 1999 Springfield - Springfield Regional Center

October 20, 1999 Jefferson City - Missouri State Capitol Building

October 21, 1999 St. Louis - St. Louis Metropolitan Psychiatric Center.

A total of 69 persons testified before the committee; 21 persons were family members, relatives or friends of individuals with a traumatic brain injury; 32 persons were medical professionals, administrators, program officials or service coordinators; 15 persons were survivors of a traumatic head injury and 1 person represented the Missouri House of Representatives.

In the next section, the dimensions of traumatic brain injury and problems affecting the traumatic brain injury community will be discussed.

Traumatic Brain Injury and Problems Identified by the Traumatic Injury Community

Section 192.735 of the 1994 Missouri Revised Statutes defines head injury or traumatic brain injury as:

> ...a sudden insult or damage to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result in a decrease in one or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurisms, and congenital defects are specifically excluded from this definition.

The etiological factors of a traumatic brain injury are motor vehicle accidents, falls (particularly by the elderly), violence (firearms and domestic) or conditions which deprive the brain of oxygen. A traumatic brain injury can occur as a result of open head injuries or closed head injuries and the severity of a traumatic head injury can range from mild to severe. Individuals with such injuries often experience post-traumatic brain injury complications which include physical limitations, cognitive difficulties and psychological difficulties.[1]

Individuals and families who testified before the Interim Committee verified the etiological factors leading to a traumatic brain injury (particularly motor vehicle accidents) and repeatedly stated that each individual case of traumatic brain injury is unique. During the public hearings, individuals with a traumatic brain injury and family members living with a person with a traumatic brain injury also identified various issues and problems they have experienced while seeking state services. Such issues and problems included social and behavioral problems experienced by individuals with a traumatic brain injury; the need for increased educational awareness of traumatic brain injury for educators, physicians and families; the mis-diagnosis of traumatic brain injury and secondary characteristics; the lack of alternative housing

arrangements for persons with a traumatic brain injury; questionable standards of care for persons with a traumatic brain injury who are placed in nursing homes; transportation problems (particularly in rural communities and isolated areas); the need for greater service coordination; the need for increased funding for traumatic brain injury services; the lack of home and community based services in certain areas in Missouri; and the effect of the Medicaid spend-down requirement, which places a financial hardship on persons with a traumatic brain injury who seek to maintain employment.

Service providers, service coordinators, program administrators and medical professionals also testified before the Interim Committee and identified various problems and issues, which included the need for the Home and Community Based Waiver; the lack of long term care programs for persons with a traumatic brain injury; problems with a change in the prior authorization requirement by the Department of Health; the increasing incidence of traumatic brain injury experienced by newborns (i.e., Shaken Baby Syndrome); establishing a Traumatic Brain Injury Trust Fund; increasing funding for traumatic brain injury services; problems with transportation; the lack of affordable housing for persons with a traumatic brain injury; the need for greater service coordination; the lack services for traumatic brain injury patients in rural communities and the need for telemedicine in rural areas.

While it is impossible to address each issue and problem articulated during the public hearings, the Interim Committee on Head Injury will address (1) the designation of a lead state agency; (2) the need for greater educational awareness; (3) the lack of appropriate treatment and services; (4) funding for traumatic brain injury services and (5) the continued monitoring of persons with a traumatic brain injury. An examination of each issue will be contained in the Recommendations Section of this report.

In the next two sections, the demographics of traumatic brain injury, financial expenditures and current state programs for traumatic brain injury will be examined.

The Demographics and Costs of Traumatic Head Injury

The problems identified by individuals, family members, providers, service coordinators, administrators and medical professionals could be compounded by the increasing number of persons experiencing a traumatic brain injury, the increased demands for traumatic brain injury services and the fragmented nature of the service delivery system for persons with a traumatic brain injury in the State of Missouri.

Demographics - National

Although the lengths of stays in hospitals and the mortality rate of persons with a traumatic brain injury have decreased in recent years due to increased and effective emergency care, effective transportation to specialized treatment facilities, and advances in acute care management, the National Institutes of Health has estimated that nationally, 2.5 million to 6.5 million persons are currently living with a traumatic brain injury and an estimated 1.5 to 2 million persons incur a traumatic brain injury yearly due to motor vehicle accidents, falls, acts of violence and sport accidents in the United States. [2]

Further, the National Institutes of Health state that 70 ,000 to 90,000 persons incur a traumatic brain injury resulting in a long term substantial loss of functioning and approximately 300,000 persons are admitted to hospitals with a mild or moderate traumatic brain injury. Traumatic brain injuries affect males twice as often as females; and the incidence is highest in the 15 to 24 year old age category and the 75 year and older age category and is a leading cause of long term disability among children and young adults. [3]

The National Institutes of Health further state that the economic impact of traumatic brain injuries in the United States "is enormous." The annual cost of acute care and rehabilitation for new cases is estimated at $9 billion to $10 billion. Estimates for the average lifetime cost of care for persons with a severe traumatic brain injury can range from $600,000 to $1,875,000.[4]

Demographics - Missouri

In Missouri, the Center for Health Information Management and Epidemiology reported that 4,280 individuals experienced a traumatic brain injury in 1996.[5] Similar to data reported by the National Institutes of Health, the Center for Health Information Management and Epidemiology reported that males experienced a higher number of head injuries (2,795) than females (1,485) and males experienced a higher incidence rate (108/100,000 persons) than females (54/100,000 persons). Individuals aged 15-24 years old had the highest incidence rate (133/100,000 persons) and persons aged 65 and over had the second highest incident rate (118/100,000 persons). African Americans and other persons of color had a higher incidence rate (96/100,000 persons) than White Americans (77/100,000 persons) in Missouri. The etiological factors resulting in a head injury in Missouri (ranked in the order of highest occurrence) in 1996 were motor vehicle accidents, falls, assaults, self inflicted and other. [6]

Demographic data obtained from the four Missouri agencies providing services to the brain injury community revealed the number of persons who have received services. The Department of Health (including divisions within the department) enrolled 535 persons at the end of fiscal year 1999. The Department of Health also reported that of the 535 persons enrolled, 380 persons were financially eligible to receive rehabilitation services.[7] Officials at the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation stated that 1,427 persons received services for federal fiscal year ending September, 30, 1999.[8] Officials at Division of Special Education, reported that 287 persons aged 5 years old through 21 years old received services as of December 1, 1997 and 292 persons aged 5 years old through 20 years old received services as of December 1, 1998.[9] Officials at the Department of Mental Health reported that as of fiscal year ending 1997, 190 persons received services.[10] Officials at the Department of Social Services, Division of Medical Services, stated that for fiscal year 1998, 144 persons with a traumatic brain injury received services through their primary program for persons with a traumatic brain injury, the Comprehensive Day Rehabilitation Program. For fiscal year 1999, 162 persons received services through the Comprehensive Day Rehabilitation Program.[11]

Costs - Missouri

Financial data on treatment costs for persons with a traumatic brain injury by agency and/or program was provided by the Department of Health, the Department of Social Services, the Department of Mental Health and the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation.

The Department of Health, Bureau of Special Health Care Needs reported the total general revenue appropriations for the stated years as follows:

FY 1998:	$723,993
FY 1999:	$932,993
FY 2000:	$982,993[12]

For fiscal year 2000, the Department of Health, Bureau of Special Health Care Needs is requesting an additional $441,381 supplemental appropriation for the purposes of funding supportive services for individuals with a traumatic brain injury. The supplemental budget request for FY 2000 was due to increased costs of services provided and the increased demand for services. The supplemental budget request will be discussed at the end of this section.[13]

The expenditures of the four most expensive programs reported by the Department of Health, Bureau of Special Health Care Needs for fiscal years 1998 and 1999 were:

	1998	1999
Functional Living	$125, 905	$125,598
Transportation	$116, 931	$280,056
In-Home Supports	$221,705	$271,380
Day Activities	$116,194	$274,306[14]

Officials at the Department of Health, Bureau of Special Health Care Needs also reported that the average number of services received per patient and the average cost

per patient with a traumatic brain injury has increased. The average number of services per patient and the average cost per patient are as follows:

Average Number of Services

1996	1.67
1997	1.68
1998	1.77
1999	2.09

Average Cost Per Patient

1996	$2,189.79
1997	$2,723.72
1998	$3,419.18
1999	$3,936.68[15]

For fiscal year 1997, officials at the Department of Mental Health reported expenditures of $2,434,199 for the 190 persons with a traumatic brain injury who received services.[16]

The Department of Social Services, Division of Medical Services reported expenditures for fiscal years 1998 and 1999 for persons who received services through the Comprehensive Day Rehabilitation Program as follows:

FY 1998	$828, 879
FY 1999	$994, 495[17]

The Department of Elementary and Secondary Education, Division of Vocational Rehabilitation reported the following expenditures for persons with a traumatic brain injury for federal fiscal years 1998 and 1999 as follows:

Basic Services

1998	$1,639,649.31
1999	$1,686,890.63

Supported Employment

1998	$163,647.80
1999	$246,686.26[18]

The average cost per case for basic support services and supported employment services as reported by officials of the Division of Vocational Rehabilitation are as follows:

Basic Support Services

1998	$1,954.29
1999	$2,042.24

Supported Employment

1998	$3,557.56
1999	$4,485.20[19]

The second division, Special Education, did not have financial data available at the time of this report.

The Interim Committee on Head Injury made a concerted attempt to obtain the most comprehensive data on the number of persons with a traumatic brain injury who were enrolled and/or eligible to receive state services during the previous two years and expenditures associated with such services.

From the data supplied by the state agencies providing traumatic brain injury services, it is evident that the number of persons with a traumatic brain injury who have received services has increased; the costs associated with such services has increased and the number of services received per patient has increased (as reported by the respective agency or division).

The effect of the increases in the number of persons requesting services and costs associated with such services caused the lead state agency for traumatic brain injury services, the Department of Health, Bureau of Special Health Care Needs, to institute measures which resulted in the non-payment of some service providers effective July 1, 1999, establishing a waiting list for new enrollees and requesting a supplemental appropriation for FY 2000. The measures negatively impacted some service providers (i.e., non-payment) and persons with a traumatic brain injury who were seeking and/or receiving state services. This issue will be discussed further in the Recommendations Section of this report.

Current State Programs and Service Delivery

The service delivery system for persons with a traumatic brain injury consist of the Missouri Head Injury Advisory Council and 22 programs dispersed among the Department of Social Services, Division of Medical Services; Department of Health, Division of Maternal, Child and Family Health (currently the lead state agency); Department of Mental Health, Division of Mental Retardation and Developmental Disabilities; and the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation and the Division of Special Education.[20]

The Head Injury Advisory Council was established in 1985 under Executive Order 85-6 by Governor John Aschroft for purposes of studying and recommending actions for public and private entities on various issues which included identifying the extent of head injury in Missouri; protecting the personal and civil rights of persons with a head injury; identifying appropriate "entry points" for head injury persons seeking state services; and developing head injury preventative education measures.[21]

In addition to Executive Order 85-6, the federal Traumatic Brain Injury Act of 1996 was passed which required states to establish advisory committees as a condition of receiving demonstration grants from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The purpose of the grants is to "improve access to health and other services regarding traumatic brain injury."[22]

The U.S. Department of Health and Human Services, Health Resources and Services Administration requires states that receive a planning grant or implementation grant to discuss how they would "enhance access to comprehensive and coordinated services for persons with a traumatic brain injury and their families"; "use existing research based knowledge and development approaches of previous traumatic brain injury grantees in meeting program goals"; and generate support for the "sustainability of funded [traumatic brain injury] projects through legislative, regulatory and policy changes which would promote the institutionalization of traumatic brain injury services for individuals and their families."[23]

In addition, states must discuss how they would examine various issues, which include the development and expansion of *core capacity components* (which include establishing

an Advisory Board); designating a coordinating agency; conducting an assessment and developing an Action Plan.[24]

In the attempt to "enhance access to comprehensive and coordinated services" and as a condition of receiving a planning grant and an implementation grant, the Missouri Department of Health, Division of Maternal, Child and Family Health (the implementation grant recipient), the Missouri Head Injury Advisory Council (in an advisory capacity) and an Interagency Committee developed a Traumatic Brain Injury Program Matrix which identifies the four main state agencies providing traumatic brain injury services (Department of Health; the Department of Mental Health; the Department of Social Services and the Department of Elementary and Secondary Education); the 22 programs and eligibility requirements; services offered; limitations and funding information.[25]

After identifying the various programs for traumatic brain injury, the Interagency Committee identified *gaps and barriers* in the service delivery system and developed *recommendations*. The gaps identified in the matrix included establishing programs for intermediate care; establishing home and community based services; the need for supports for community living; the lack of psychological and substance abuse services in rural areas; and creating behavioral services for crisis management. Barriers identified in the program matrix included the need for greater educational awareness; establishing a special needs assessment procedure during the interview process for persons identified with a traumatic brain injury; the provision of different benefits for persons with a traumatic brain injury who are school aged and those 21 years of age or older; and the lack of supported employment in rural areas. [26]

The Interagency Committee also identified the following recommendations which included developing an educational committee to work with the Missouri Bar Association regarding the management of persons with a traumatic brain injury who violate the law and developing an intervention program to prohibit such persons from violating the law; assessing client needs; developing neuro-behavioral, psychological and substance abuse services; developing a data system across departments; evaluating the services received by children and those received by adults; reviewing the transportation agreements; and examining supported employment services.[27]

The Interagency Committee also developed an Interagency Action Plan. The Action Plan (which contained recommendations identified in the matrix) is required as a condition of receiving the implementation grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The implementation grant is used for the primary objective of "improving and enhancing access to state [traumatic brain injury] services."[28]

In the Recommendation Section, the Interim Committee will examine the designation of the lead state agency responsible for coordinating state services. The Interim Committee will also discuss recommendations which will affect the service delivery system in Missouri.

Recommendations

The 1999 Interim Committee on Head Injury, charged with examining the current state structure of service delivery for the traumatic brain injury community in the state of Missouri, respectfully submits the following recommendations. The implications of designating a lead state agency are discussed followed by a recommendation. Additional recommendations will be discussed under the Programmatic Issues subsection.

At the outset, the Interim Committee would like to thank members of the traumatic brain injury community, medical professionals, program administrators, state policy makers (past and present) for participating in the public hearings and for facilitating discussions for improving the life chances of individuals affected with a traumatic brain injury in Missouri.

Designating a Lead State Agency

In Missouri, a major issue which was discussed during a meeting commenced by the Missouri Head Injury Advisory Council and during the public hearings was the designation of the lead state agency responsible for coordinating state services for the traumatic brain injury community. The designation focused on two state departments, the Department of Mental Health and the Department of Health. [29]

A key problem confronting the Traumatic Brain Injury Program, irrespective of the location of the lead agency, is the issue of "under-funding,"[which would place a burden on any agency].[30] This issue will be examined later in this section.

Department of Mental Health

The Department of Mental Health, Division of Developmental Disabilities currently provides a range of services to persons who have been certified to have mental retardation and/or a developmental disability (which includes a head injury) before the age of 22 years.[31]

An official at the Department of Mental Health, Division of Mental Retardation and Developmental Disabilities emphasized a number of critical issues which would affect the service delivery system for persons receiving services through the division and for persons with a traumatic brain injury, aged 22 years or older who would be incorporated into the division's service delivery system if a state statutory change is made to include persons with a traumatic brain injury.

First, the primary inclusion of persons injured after the age of 22 years with a traumatic brain injury into the Division of Mental Retardation and Developmental Disabilities would be inconsistent with the division's philosophy. The programmatic philosophy of the division is *habilitation;* for the traumatic brain injury community, the programmatic philosophy is *rehabilitation*.[32]

Second, the addition of the traumatic brain injury community (persons injured after the age of 22 years) under the Division of Mental Retardation and Developmental Disabilities "would not" result in the immediate provision of services for this population. This population would be placed on a waiting list, currently containing about 1,700 persons who have a developmental disability with an estimated wait time of 2-3 years, subject to the "current head injury appropriation."[33]

Third, persons with a traumatic brain injury, who were injured after the age of 22 years would not be eligible to receive home and community based services under the Mental Retardation and Developmental Disabilities Waiver, 1915 (c) of the Social Security Act (which will ensure federal matching dollars) due to the facts that changing the

Missouri statute to include persons injured after age the of 22 years would not change the federal statutes pertaining to the mental retardation and developmental disabilities definition and that this waiver is based on the provisions pertaining to intermediate care facilities for the mentally retarded.[34]

Finally, the brain injury community "is opposed" to having the Division of Mental Retardation and Developmental Disabilities designated as the lead state agency and that "changing" the *developmental disability definition* contained in the Missouri Revised Statutes [could meet] with "enormous controversy."[35]

In summation, after considering the implications of designating the Department of Mental Health as the lead state agency and changing the Revised Statutes of the State of Missouri to include persons injured after the age of 22 years into the service delivery system, the Interim Committee on Head Injury has determined that revising the Missouri statutes governing the Division of Mental Retardation and Developmental Disabilities and designating the division as the lead state agency could have the potential for disrupting the current provision of services for persons with a traumatic brain injury and would conflict with the guiding philosophy of the traumatic brain injury community. Finally, the designation would go against the wishes of members of the traumatic brain injury community, who are opposed to the potential designation.

Department of Health

In 1991, the Missouri General Assembly passed House Bill 218 and Senate Bill 125 & 341 which established the Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services within the Department of Health. The division served as the lead state agency and was responsible for various programs which included "ensuring that injury prevention and head injury rehabilitation, evaluation, case management, treatment, rehabilitation and community support services were accessible, whenever possible."[36]

In 1995, the division was abolished and the responsibilities were assigned to the Division of Maternal, Child and Family Health, which has served as the lead state agency since the reorganization. The main purpose of the lead state agency is to

coordinate services provided by various state agencies for persons with a traumatic brain injury in Missouri. The Department of Health also provides a range of services for persons with a traumatic brain injury.[37]

To facilitate the coordination of state services for persons with a traumatic brain injury, the Division of Maternal, Child and Family Health has received a Planning Grant and Implementation Grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration. The division is in the third year of the implementation grant which is used for the purpose of achieving the goal of "improving and enhancing access to services for persons with a traumatic brain injury and their families."[38] Currently, the Department of Health has employed a Program Manager for Brain Injury Services who is responsible (in cooperation with state agencies providing brain injury services) for achieving this goal.

The implementation grant requires the Division of Maternal, Child and Family Health, Bureau of Special Health Care Needs to conduct an *assessment of* persons with a traumatic brain injury and to develop an *action plan for a community based system of care* in cooperation with other state agencies who provide services to persons with a traumatic brain injury.[39]

Under the direction of the Missouri Head Injury Advisory Council and the Division of Maternal, Child and Family Health, Bureau of Special Health Care Needs, an Interagency Committee was established which created a matrix of current services provided in the state of Missouri for persons with a traumatic brain injury.[40] After identifying the various programs for persons with a traumatic brain injury, the committee developed an Interagency Action Plan, based on the recommendations developed in the program matrix. The Interagency Action Plan is a statewide plan for "developing a comprehensive, community- based system of care which should encompass physical, psychological, educational, vocational and social aspects of traumatic brain injury services and addresses the needs of persons with a traumatic brain injury and their families."[41]

The current designation of the Department of Health, the Division of Maternal, Child and Family Health as the lead state agency follows the traditional medical perspective for treating and rehabilitating persons with a traumatic brain injury.[42] However,

research has also shown that in addition to the medical perspective, rehabilitation should include vocational rehabilitation, rehabilitation within schools, independent living programs, supported employment, day programs, case management and consumer peer support programs.[43] In Missouri, rehabilitative programs are currently in place or have been identified as "gaps" by the Department of Health, Bureau of Special Health Care Needs and cooperating state agencies or are currently being recommended.

During the public hearings, the Interim Committee received materials and heard testimony from officials at the Department of Health that the agency has initiated actions "for improving and enhancing access to services" for the traumatic brain injury community. However, the Interim Committee also heard testimony from some individuals in the traumatic brain injury community (including the Department of Health) that (1) the service delivery system is fragmented; (2) communication across state agencies (*i.e., Department of Health; Department of Mental Health; Department of Elementary and Secondary Education, Department of Social Services and the Missouri Head Injury Advisory Council*) needs improvement; (3) inequities exist in the service delivery system for persons who experience a traumatic brain injury before the age of 22 years and those after the age of 22 years (persons can receive services from the Department of Mental Health or the Department of Health); (4) the change in the prior authorization requirement resulted in the non-payment of some service providers and (5) the service needs of the traumatic brain injury community "were not a priority."

Recommendation: Lead State Agency

As such, the Interim Committee recommends that the State of Missouri **continue to examine methods and program models for improving the integration of services and to coordinate funding and eligibility criteria for persons seeking traumatic brain injury services and to provide a more complete range of services for appropriate rehabilitation and support for individuals with a traumatic brain injury.**

This recommendation may result in a future designation of a new lead state agency or new model *for coordinating* services and funding to improve the service delivery system for traumatic brain injury survivors, their families and for service providers in

Missouri; and to improve the communication among agencies and between state agencies and the Missouri General Assembly.

Programmatic Issues

Additional recommendations of the Interim Committee on Head Injury will be addressed in the following areas which include the need for greater educational awareness of traumatic brain injury; the lack of appropriate treatment and services; funding for traumatic brain injury services and continued monitoring of persons with a traumatic brain injury. The Interim Committee on Head Injury notes that *some* of the recommendations are listed in the statewide Interagency Action Plan.

Greater Awareness of Traumatic Brain Injury

Members of the Interim Committee on Head Injury consistently heard from members of the traumatic brain injury community that greater educational awareness of traumatic brain injury was needed for medical personnel, educators at the primary and secondary educational levels, families and policy makers in Missouri.

Some members of the traumatic brain injury community testified that when seeking treatment for their traumatic brain injury, they were mis-diagnosed, and at times, prescribed various medications which prolonged their efforts at rehabilitation.

The Head Injury Advisory Council and coordinating state agencies should continue to investigate methods for raising the awareness and implications of traumatic brain injury in the medical community.

Some members of the traumatic brain injury community also testified at the public hearings that increased educational awareness was needed by educators at the primary and secondary levels in order to facilitate the placement of brain injured persons in a supportive and appropriate learning environment.

Currently, efforts to increase the educational awareness among educators have been taken by the Missouri Head Injury Advisory Council and cooperating government agencies (federal and state) through the recent publication entitled, *Educational*

Directions for Students with Traumatic Brain Injury and the publication (developed with members from cooperating state agencies) entitled *Recommendations for Meeting the Needs of Children and Youth with Traumatic Brain Injury.*

The State of Missouri, in cooperation with federal, state agencies and the Missouri Department of Elementary and Secondary Education should continue to promote educational awareness among educators.

Finally, efforts to increase the awareness of traumatic brain injury among families with a traumatic brain injury survivor and state policy makers have been initiated by the Missouri Head Injury Advisory Council and cooperating state agencies through the dissemination of various pamphlets and information packets on traumatic brain injury, available programs and state funding sources for persons with a traumatic brain injury (e.g., *Head Injury: Missouri Resource Packet for Survivors, Families and Caregivers* and *Rating Health Care Plans in the Care of Patients with a Traumatic Brain Injury*).

In addition, the Missouri Head Injury Advisory Council has compiled a voluminous resource guide entitled, *Reference Guide* for state legislators, legislative staff and agency officials. The guide contains information and reports on traumatic brain injury, federal and state laws concerning traumatic brain injury, state government organization and federal demonstration grants.

Lack of Appropriate Treatment and Services

The Interim Committee on Head Injury has reviewed the program matrix and Action Plan of the Department of Health, Division of Maternal, Child and Family Health, Bureau of Special Health Care Needs, in conjunction with the Interagency Committee on Traumatic Brain Injury, and agrees that "gaps and barriers" exist in the service delivery system which include the Home and Community Based Waiver; different benefit packages for school aged and persons 21 years and older with a traumatic brain injury; the lack of psychological and substance abuse services in rural areas; the lack of neuro-behavioral services and developing a behavioral unit for crisis management.[44]

Recommendation: Home and Community Based Waiver

The Department of Social Services, Division of Medical Services (with cooperation from the Department of Health, Division of Maternal, Child and Family Health) should continue to examine the possibilities (e.g., per capita expenditures; needed services, personnel; administrative capacity and simplicity) of applying for a Home and Community Based Waiver from the U.S. Department of Health and Human Services, Health Care Financing Administration, as discussed under Section 1915(c) of the Social Security Act. Various services could be provided to a small group of targeted individuals with a traumatic brain injury as stated in Section 1915 (c) of the Social Security Act or additional services can be determined by the Department of Social Services, Division of Medical Services, subject to the approval of the Secretary of the U.S. Department of Health and Human Services.[45]

Recommendation: Telemedicine

In the area of developing psychological and substance abuse services for traumatic brain injury survivors in rural areas, the lead agencies (Mental Health, Health, the University of Missouri-Columbia, School of Medicine), cooperating agencies and providers should continue to examine the implications for using telemedicine in rural areas which lack such specialized services.

Recommendation: Children Services

The Department of Health, Bureau of Special Health Care Needs, should continue to examine the provision of traumatic brain injury services and benefits for school aged and persons 21 years or older. The issue was repeatedly raised during the public hearings by individuals from the traumatic brain injury community who stated that such services were inequitable. Further, the Missouri Head Injury Advisory Council has identified issues confronting children and youth in a 1998 report entitled, *Recommendations for Meeting the Needs of Children and Youth with a Traumatic Brain Injury.*

Recommendation: Nursing Home Placements; Crisis Management Services

The Interim Committee on Head Injury was also informed by family members of traumatic brain injury survivors that individuals placed in nursing homes received sub-standard care from some employees. As such, the Department of Health and the Department of Social Services should consider examining this critical issue in greater detail.

The Department of Mental Health and the Missouri Head Injury Advisory Council should continue efforts for developing a behavioral services/crisis management system (in conjunction with the Missouri Bar Association) for persons with a traumatic brain injury who could experience post-secondary conditions such as entering the criminal justice system as indicated in the Interagency Action Plan.

Recommendation: Neuro-behavioral Services; Reimbursement Policies

Regarding the development of neuro-behavioral unit, efforts should be coordinated with the University of Missouri-Columbia, School of Medicine, Division of Clinical Health Psychology and Neuropsychology in order to provide this specialized treatment to traumatic brain injury survivors in the state of Missouri.

To fulfill this effort, the state of Missouri needs to increase the numbers of neuropsychologists in the state by providing incentives for education and practice within the state.

The state of Missouri should also examine funding and reimbursement policies for services required for full rehabilitation for individuals with a traumatic brain injury.

Funding for Traumatic Brain Injury Services

The appropriation for rehabilitation services to the Department of Health has been a consistent amount of $588,323 for the last three fiscal years of 1997 through 1999. In addition, there has been an apparent low priority ranking of traumatic brain injury services in the Department of Health, Bureau of Special Health Care Needs.

In spite of these issues, there has been an increase in the number of eligible traumatic brain injury survivors who receive more than one service, an increase in the average cost per patient receiving services and an increase in the costs of traumatic brain injury services which resulted in a change in processing the traumatic brain injury prior authorization requests by the Department of Health (from monthly to quarterly). As a result, 58 clients were placed on a waiting list, denials of requests for traumatic brain injury services occurred and the non-payment of some service providers (this was revealed during the public hearings) also occurred.[46]

As a result, the Department of Health is requesting a supplemental appropriation of $441,381 FY 2000 which would allow the department to provide services for about 120 individuals.[47] However, during the public hearings, some service providers testified that payments for services already provided to persons with a traumatic brain injury were terminated.

Recommendation: Funding for Services

As such, the Interim Committee on Head Injury recommends that the Department of Health should request an increase in appropriations for traumatic brain injury services. The department should honor the existing service contracts of service providers who did not receive payment due to the change in processing prior authorizations (provided that the providers followed the correct procedures for filing the claims). The Interim Committee supports the request for supplemental appropriations FY 2000 in order to provide services for individuals with a traumatic brain injury.

Recommendation: Trust Funds

The State of Missouri should explore the creation of a Traumatic Brain Injury Trust Fund (subject to appropriations from the Missouri General Assembly). It had been suggested during the public hearings that Missouri should consider creating a trust fund financed from motor vehicle violations which is currently done in various states such as California and Florida. However, this proposal would require amending the Missouri Constitution (Article IX, Section VII).

Currently, funds obtained from motor vehicle violations are deposited into the County School Fund.

Another funding alternative discussed was the utilization of the Missouri Family Trust. This fund is established in the Missouri statutes as discussed in section 402.199 through 402.225 and sections 473.657 and 475.093 *RSMo., Supp, 1999*. Monies contained in this fund cannot be used by state agencies when determining eligibility for Medicaid, "unless prohibited by federal statutes or regulations." The use of this trust is limited to persons eligible to receive services through the Department of Mental Health or for families, friends, and guardians of persons with a "disability" who establish a fund for a beneficiary. Therefore, this source of supplemental funding for traumatic brain injury services should be examined by families, friends and guardians of persons with a traumatic brain injury in order to improve the quality of life for such individuals.

Recommendation: Budgetary Practices and Inter-agency Communication

The Interim Committee recommends that the Department of Health, Bureau of Special Health Care Needs, continue to improve its budgetary practices, prioritization of services and inter-agency communication between the Missouri Head Injury Advisory Council, the Department of Mental Health, the Department of Social Services and the Department of Elementary and Secondary Education who provide services for the traumatic brain injury community.

Continued Monitoring of Persons with a Traumatic Brain Injury

The Interim Committee on Head Injury recommends that the Department of Health and cooperating state agencies should continue to effectively monitor all causes of traumatic brain injuries in Missouri.

The Interim Committee on Head Injury recognizes that the Department of Health, Center for Health Information Management and Epidemiology receives reports on the incidence of head injuries and spinal cord injuries in Missouri as required by section 192.737 *RSMo.*[48]

The Center for Health Information Management and Epidemiology has published a report on the incidence of head and spinal cord injuries which is entitled, *Missouri Head and Spinal Injury Registry Report, 1996.* This report revealed that under-reporting was a problem and could affect the tabulations of data concerning the incidence of head injuries in Missouri.[49]

It is anticipated that increased educational awareness of the nature of head injuries in the medical community and improved reporting by Missouri acute care hospitals and rehabilitation hospitals will minimize and/or eliminate the occurrence of under-reporting.

As indicated in the Head Injury Program Matrix and the Interagency Action Plan, the Interim Committee also agrees that a data system needs to be developed "across state agencies" in order to facilitate improved communication across departments. The Interim Committee anticipates that the data system will minimize and/or eliminate errors which could occur in the application/eligibility process for persons with a traumatic brain injury; improve record-keeping (e.g., current) statistics; numbers of persons receiving services, the types of services, the number of services and facilitate the development of outcomes measures for persons with a traumatic brain injury seeking rehabilitation.

Conclusion

The Interim Committee on Head Injury agrees that the implementation of the recommendations will facilitate the development of an improved service delivery system for traumatic brain injury survivors, families and service providers in Missouri.

Again, the Interim Committee on Head Injury would like to thank members of the traumatic brain injury community, medical professionals, program administrators, state policy makers (past and present) for participating in the public hearings and for facilitating discussions for improving the life chances of individuals affected with a traumatic brain injury in Missouri.

Appendix C
Staff of Interim Committee on Head Injury

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Endnotes

1. Missouri. Office of Administration. Missouri Head Injury Advisory Council. *Overview of Traumatic Brain Injury*, p. 4; pp. 11-16.

2.U.S. Department of Health and Human Services. National Institutes of Health. *Consensus Development Conference Statement: Rehabilitation of Persons with a Traumatic Brain Injury, October 26-28, 1998, pp. 2-3.*

3.Ibid., pp. 4-6.

4.Ibid., p. 8. The National Institutes of Health indicates that the figures underestimate the economic burden to families and society because they do not include lost earnings, costs to social service systems and the lost earnings of family members who care for persons with a traumatic brain injury.

5.Missouri. Department of Health, Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report, 1996, Table 3-A, p. 17.* This number includes the number of non-admitted deaths and individuals admitted to Missouri acute care and rehabilitation hospitals.

6.Missouri. Department of Health, Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report, 1996, Figures 3, 5,and 6, pp. 4-5. The actual number of traumatic brain injuries for individuals aged 15-24 years in 1996 was 982; for individuals aged 65 and over was 872.* The number of head injuries experienced by White Americans in Missouri in 1996 was 3,609 persons and the number of African Americans and other persons of color who experienced a head injury in 1996 was 650 persons. For the number of head injury occurring in an etiological category, see Tables 3-B, 3-C, 3-D, 3-E and 3-F, pp. 18-22.

7.Missouri. Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program,* October 15, 1999. The 380 persons eligible to receive rehabilitation services for fiscal year 1999 included persons who received services; persons who did not receive services and persons who received services through another agency. The remaining 155 persons were individuals who received service coordination only. In 1998, the total number of persons enrolled in the Department of Health was 379 persons of which 228 persons were eligible to receive rehabilitation services.

8.Missouri. Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. *Traumatic Brain Injury Consumers for the State of Missouri: A Statistical Report FY 1999.* This figure includes the successful and non-successful closures as well as those

receiving enrolled at the end of the fiscal year.

9.Missouri. Department of Elementary and Secondary Education, Division of Special Education. *Information on Traumatic Brain Injury, December 1, 1998.* Information for year ending December 1, 1997 was provided by telephone by Ms. Lina Browner, Division of Special Education on November 12, 1999.

10.Missouri. Department of Mental Health. Division of Mental Retardation and Developmental Disabilities. *Information on Traumatic Brain Injury for the State of Missouri, Fiscal Year 1997.* Information for 1998 and 1999 were not available at the time of this report.

11. Missouri. Department of Social Services, Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury, Fiscal Years 1998 and 1999.* The information was obtained through a telephone conversation with Ms. Diane Tackett, of the Division of Medical Services on November 17, 1999.

12.Missouri. Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program,* October 15, 1999.

13. Ibid.

14.Ibid.

15.Ibid.

16.Missouri. Department of Mental Health, Office of the Director of the Division of Mental Retardation and Developmental Disabilities. *Demographic and Financial Data for Persons with a Traumatic Brain Injury. Fiscal Year 1997.*

17. Missouri. Department of Social Services, Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury, Fiscal Years 1998 and 1999.* Expenditure information was obtained through a telephone conversation with Ms. Diane Tackett, of the Division of Medical Services on November 17, 1999.

18.Missouri. Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. *Financial Information on Basic Support Services and Supported Employment Services for Persons with a Disability, 1998-1998.* The figures for basic support services were based on 839 persons and 826 persons for 1998 and 1999. The figures for supported employment were based on 46 persons and 55 persons for 1998 and 1999.

19.Ibid.

20. See Appendix A for a complete listing of state services for persons with a traumatic brain injury which was compiled by the Missouri Department of Health, Bureau of Special Health Care Needs, October, 1999.

21.Missouri. General Assembly. 1985. *Joint Interim Committee on Head Injury: Report and Recommendations*, p. B-1.

22.U.S. Government. House of Representatives. *Traumatic Brain Injury Act of 1996, Public Law 104-652.*

23.U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, September, 1999,* p. 2.

24.Ibid., p. 3.

25.Missouri. Department of Health. Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October 1999.*

26.Ibid.

27.Ibid.

28. U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, September, 1999,* p. 11.

29. The Missouri Head Injury Advisory Council meeting was held September 27, 1999.

30. Missouri. Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

31. Missouri. Department of Health. *Traumatic Brain Injury Program Matrix*, October 1999.

32. *State of Missouri, Revised Statutes, 1998, section 630.005 (13).* Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

33. Ibid., *Solomon.*

34. Missouri, Department of Health, Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October 1999.* Section 1915 (c) of the Social Security Act does allow a

state agency (i.e., the Department of Social Services) to apply for a *Traumatic Brain Injury, Home and Community Based Waiver*. See the federal statutes, 42 U.S.C., Section 6001 (8), 42 C.F.R., Section 435.1009 and 42 U.S.C.A., Section 1396 n (c).

35.Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

36.Missouri General Assembly, 1991. House Bill 218 and Senate Bill 125 & 341.

37.Missouri. Department of Health, Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October, 1999.*

38. U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, FY 1999,* p. 11.

39.Ibid., pp. 1-4.

40.The Interagency Committee consisted of representatives of the Missouri Head Injury Advisory Council, the Department of Social Services, the Department of Mental Health and the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation.

41. U.S. Department of Health and Human Services, Health Resources and Services Administration, *Application Guide for Traumatic Brain Injury, State Demonstration Grant Program,* September, 1999, p. 3.

42.U.S. Government, National Institutes of Health. *Report of the Consensus Development Conference Statement for Rehabilitation of Persons with a Traumatic Brain Injury. October 26-28, 1998,* p. 12.

43.Ibid., p. 14.

44.Missouri, Department of Health. *Traumatic Brain Injury Program Matrix, October 1999; Interagency Action Plan, September, 1999.*

45. U.S. Government, General Accounting Office. *Traumatic Brain Injury: Programs Supporting Long Term Services in Selected States, February, 1998, pp. 6-9.* For a discussion of the Home and Community Based Waiver, see U.S.C.A. Section 1396 n(c).

46.Missouri. Department of Health. *News Release: Department Will Seek Supplemental Funding For Head Injury Services, 21 July 1999;* Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program,* October 15, 1999; Department of Health, Bureau of

Special Health Care Needs, Letter from A. Diane Poole to Traumatic Brain Injury Service Providers, 25 June, 1999.

47.Ibid.

48.This provision contains state statutes pertaining to the Head and Spinal Cord Injury Registry.

49.Missouri. Department of Health. Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report*, 1996, p. 1.

Bibliography

Missouri - Executive

Missouri. Department of Elementary and Secondary Education. Division of Special Education. *Information on Traumatic Brain Injury.* Jefferson City, December 1998.

Missouri. Department of Elementary and Secondary Education. Division of Vocational Rehabilitation. *Financial Information on Basic Support Services and Supported Employment Services for Persons with a Disability, 1998-1999.* Jefferson City, 1999.

_____. *Traumatic Brain Injury Consumers for the State of Missouri: A Statistical Report.* Jefferson City, 1999.

Missouri. Department of Health. Bureau of Special Health Care Needs. *The Adult Head Injury Program.* Jefferson City, 1999.

_____. *Interagency Action Plan.* Jefferson City, September, 1999.

_____. *Letter from A. Diane Poole to Traumatic Brain Injury Services Providers.* Jefferson City, 25 June, 1999.

_____. *Traumatic Brain Injury Program Matrix.* Jefferson City, October, 1999.

Missouri. Department of Health. Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report.* Jefferson City, 1996.

Missouri. Department of Health. *News Release: Department Will Seek Supplemental Funding for Head Injury Services.* Jefferson City, 21 July 1999.

Missouri. Department of Mental Health. Division of Mental Retardation and Developmental Disabilities. *Information on Traumatic Brain Injury for the State of Missouri.* Jefferson City, 1997.

Missouri. Department of Mental Health. Office of the Director of Mental Retardation and Developmental Disabilities. *Demographic and Financial Data for Persons with a Traumatic Brain Injury.* Jefferson City, 1997.

_____. *Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September, 1999.*

Missouri. Office of Administration. Head Injury Advisory Council. *Overview of Traumatic Brain Injury*. Jefferson City, 1994.

Missouri. Department of Social Services. Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury*. Jefferson City, 1998.

_____. *Statistics on Persons with a Traumatic Brain Injury*. Jefferson City, 1999.

Missouri - Legislative

Missouri. General Assembly. *An Act to Create a Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services*. 86th General Assembly, H.B. 218 (28 August, 1991).

_____. *An Act Relating to Driving While Intoxicated*. 86th General Assembly, S.B. 125 & 341 (28 August, 1991).

Missouri. General Assembly. Joint Interim Committee on Head Injury. *Joint Interim Committee on Head Injury: A Report and Recommendations*. 1985.

Missouri - Other

Missouri. *Revised Statutes, 1994.*
_____. *1999 Supplement.*

U.S. Government - Executive

U.S. General Accounting Office. *Traumatic Brain Injury: Program Supporting Long Term Services in Selected States*. Washington, D.C., 1998.

U.S. Department of Health and Human Services. Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program*. Washington, D.C., 1999.

U.S. Department of Health and Human Services. National Institutes of Health. *Consensus Development Conference Statement: Rehabilitation of Persons with a Traumatic Brain Injury.* Washington, D.C., 1998.

U.S. Government - Legislative

U.S. Congress. House of Representatives. *Traumatic Brain Injury Act of 1996*, 104th Congress, *Public Law 104-652*.

U.S. Government - Other

Definitions Relating to Institutional Status. 42 Code of Federal Regulations, Section 435.1009.

U.S. Department of Health and Human Services. Health Care Financing Administration. Home and Community Based Waiver. 42 U.S. Code (Annotated), Section 1396 n (c).

Programs for Persons with Disabilities. U.S. Code, Section 6001 (8).

Appendix A

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
Department of Social Services, Division of Medical Services ➢ Comprehensive Day Rehabilitation Program	• 208.152 (20) RSMo • Program governed by Medicaid policy as stated by DMS in the provider manual and bulletins.	Under 21 medically necessary services are covered: • Psychologist/Neuro-psychologist • Speech therapy • Physical therapist • Occupational therapy • Counselor: psychologist/social worker or licensed professional counselor • Case Manager (BSHCN) Over 21: • Psychologist/Neuro-psychologist over 21 covered only in a FQHC or RHC • Counselor covered only in a FQHC or RHC • Speech therapy covered only in conjunction with adaptive equipment • Case manager (DOH TBI case mangers)	Must be Medicaid eligible	• Medically necessary services are covered for under 21 years of age, not limited to 1 year. Services for over 21 years of age are limited to 1 year. • Services must be provided in a free standing rehabilitation center or in an acute hospital setting with space dedicated to head injury rehabilitation. • Providers must be approved by the Division of Medical Services	• 40% GR • 60% Federal (Medicaid)	• Definition of "recent" is 5 years or less post injury • No increase in per diem rate since 1989. $110 for full day, $65 for half day
➢ EPSDT	• 208.152 RSMo • PL 53101-239 and subsequent federal regulations	Under 21 medically necessary services are covered: • Psychologist/Neuro-psychologist • Speech therapy • Physical therapist • Occupational therapy • Counselor: psychologist/social worker or licensed professional counselor • Case Manager (BSHCN) • Private Duty Nursing	Must be Medicaid eligible			
➢ Physical Disabilities Waiver (Private Duty)	1903(c) of the Social Security Act – Model Waiver	Under 21 No waiver required: • Private duty nursing services • Supplies such as diapers, underpads, gloves Over 21 waiver required: • Private duty nursing (medically Necessary) • Specialized medical equipment and supplies • Case management (BSHCN)	• Must have received or been eligible to have received private duty nursing services under EPSDT. • NF 18 points plus medical criteria must also be met.	Waiver required for services provided for over 21.		For over 21, cost effectiveness off set established against ICF/MR placement costs. Currently approved for 14 slots beginning July 1, 1999, 18 slots beginning July 1, 2000 and 20 slots beginning July 1, 2001.

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
➢ Independent Living Waiver (pending)			• Eligibility determined by Vocational Rehabilitation • 16-64 years old • NF 18 point criteria			Self directed personal care model under development, CIL. Waiver application pending at HCFA. Request is to serve individuals from age 16-64.
➢ Community Psychiatric Rehabilitation (CPS)						Program administered by DMH. DSS is flow through for Medicaid funds. Behavioral Health Carve Out Initiative is pending offers psychological and substance/alcohol abuse services to permanent and total disabled persons.
➢ Comprehensive Substance Treatment and Rehabilitation (CSTAR) ➢ Mental Retardation / Developmental Disabilities Waiver	• 208.152 RSMo			Services not provided through waiver if provided through the school	• 40% GR • 60% FED	Program administered by DMH Program administered by DMH
➢ Personal Care Services (In home)	• DMS at 13 CSR-70 - 91.010 • 208.152 (18) RSMo	• Services must be medically necessary. • Can receive Personal Care Services while attending the Comprehensive Day Rehabilitation program, but not during the same hours.	Authorized by Division of Aging Case Managers (capped, not more than nursing home)	• Limited to approximately 120 hours per month. • Not limited to a percentage of NF reimbursement for children. • Limited to 60% of the NF cap for regular Personal Care and 100% limitation for Advanced Personal Care for recipients over 21 years of age.	Division of Aging has Social Services Block Grant funding that parallels the personal care program.	
➢ Non Emergency Transportation	• 42CFR431.53 • 42CFR440.170 • 208.152 RSMo	• NEMT is covered for all Medicaid recipients for Medicaid covered services except Comprehensive Day Rehabilitation Program for all ages			Arrangements for DOH to collect the federal match were made by interagency agreement.	Interagency Agreement with DOH to provide transportation for Comprehensive Day Rehabilitation Program.

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
➢ Nursing Facilities	• CFR-483.100 - 138 • 208.152 (4) RSMo		TBI survivors who are injured prior to age 22 are subject to a Level II screening under the Pre-admission Screening and Resident Review process prior to entrance into a nursing home unless admitted under a special admissions category.			• Interagency agreement between DSS and DMH • PASARR Regulation - revision pending
<u>Department of Health, Division of Maternal, Child & Family Health</u> ➢ Bureau of Special Health Care Needs - Children with Special Health Care Needs	• 201.101-201.130 RSMo • 19CSR40-1.010 to 40-1.080	• Acute Care/Inpatient Services • Emergency Care • Physical Therapy* • Occupational Therapy* • Speech Therapy* • Nutritionist* • MSW* • Psychologist* • Outpatient Services • Prescription Medications • Durable Medical Equipment† • Medical Supplies *evaluation requires prior authorization † prior authorization needed if purchase/repair exceeds $500 or more	Based on the following: • Medical diagnosis of TBI • Financial eligibility (does not exceed 185% of federal poverty level) • Must be less that 21 years of age • Participants exceeding the financial eligibility may continue to receive service coordination services	• Must use CSHCN approved providers • Must use CSHCN formulary for prescription medication services • Some services must be prior authorized • Services not available until coma is resolved to the point of voluntary response	GR/MCH Block	• CSHCN participants are required to apply for Medicaid • CSHCN will be billed only after 3rd party sources have been satisfied

➢ Bureau of Special Health Care Needs - Healthy Children & Youth (HCY)	• Cooperative agreement between DOH and DSS/DMS
	• 208.152 RSMo
		• Medically necessary services
		• These services are authorized by BSHCN staff:
		  • Private Duty Nursing
		  • Personal Care Aide
		  • Advanced Personal Care
		  • Home Health Skilled Nursing
		  • Home Health Aide
		  • Therapies exceeding 5 times per week
		  • Medical supplies exceeding $300 per month
		  • Augmentative/communication evaluations
			• Less than 21 years of age
			• Must be Medicaid eligible
				• Must use Medicaid providers
				• Services must meet Medicaid reimbursement criteria
					• Services are paid 100% by Medicaid
					• Service coordination services funded as follows:
					  • Skilled professional medical personnel reimbursed at 75% by DSS/DMS, 25% by BSHCN
					  • Administrative costs reimbursed at 50% by DSS/DMS, 50% by BSHCN
						No respite services

➢ Bureau of Special Health Care Needs - Service Coordination	• 199.003 RSMo mandates responsibility to DOH • BSHCN Policy (7.7.4)	• Service Coordination	• Age 21+ (policy) • Medical: Must have traumatic brain injury (TBI)	TBI defined in 192.735 RSMo as "a sudden insult to the brain or its coverings, not of a degenerative	HB 10.735, DOH receives General Revenue Funds to provide Head Injury Service Coordination	

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
	describes participants served through the Head Injury Program		as defined by state statute.	nature". Such insult may produce an altered state of consciousness and may result in a decrease of one (1) or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurysms and congenital deficits shall be specifically excluded from this definition	Activities. Federal reimbursement for Administrative Case Management for Medicaid eligible (interagency agreement)	
• Bureau of Special Health Care Needs Rehabilitation Services	199.003 RSMo mandates responsibility to DOH to implement accessible programs/services.	• Rehabilitation Services: • Functional Living Rehabilitation: Residential or outpatient intensive rehabilitation for clients who have completed acute rehabilitation. Emphasis is on functional living skills, adaptive strategies for cognitive, memory or perceptual deficits, and appropriate interpersonal skills. Generally five days/week. • Physical, occupational and speech therapies: Rehabilitation therapies emphasizing restoration of motor skills associated with use of upper and lower extremities, organizational skills, speech/language abilities. • Transportation: Travel to and from head injury services funded through the Head Injury Program or Medicaid. Transportation for Medicaid-eligible clients over age 21. • In-home support: Qualified staff provides instruction/training in the performance of tasks necessary for independent living, such as grooming and hygiene,	• Financial: For rehabilitation services only. 185% of poverty level • Recipient eligible for Medicaid Comprehensive Day Program must apply.	• Services may not be component of another DOH or Medicaid Program. • Service provided only as means of attending DOH or Medicaid head injury program. • Limit of 10 hours/week. Maximum of six (6) months.	HB 10.735, DOH receives General Revenue Funds to provide Head Injury Rehabilitative Services. In addition, DOH uses some of the Medicaid Administrative Case Management Revenues to pay for Rehabilitative Services. • Inter-agency agreement between DOH and DSS/DMS allows 50% reimbursement for non-emergency transportation.	• Services are provided according to Provider Manual • 185% of poverty level instructed by Legislature • Medicaid Comprehensive Day Program available for those who are eligible • Interagency Agreement may need to be revisited

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
		meal preparation, household maintenance and budgeting. Services are provided on a one-to-one basis in the home. • Day Activity Rehabilitation: Program assists the client to become independent in the community, emphasizing independent living skills, acquisition of compensation strategies for cognitive and memory deficits, and basic self care needs. Meets 3-5 days/week. • Day Program: Program offers therapeutic, rehabilitative and social activities for clients who have completed other rehabilitation programs, and are not yet ready to enter employment of a training program. • Personal Care: Services focus on personal physical needs of the client to enable the client to remain in his/her home. • Community support: Individual assistance to clients to facilitate access to needed community services, such as financial, medical, housing and mental health services. • Counseling: Professional services providing client/family interaction toward therapeutic goals. • Recreation: Services to improve or maintain physical, mental,		• Must be at least 3 days/week for 6-8 hours/day. • Plan of care must be provided and updated after 6 months. • Maximum of 1 year. • Program must be regularly scheduled. • Does not include summer camps, on-site job training programs, professional service facilities such as offices of physicians or therapists, and programs that operate solely for social welfare functions (nutrition/meal sites, food/clothing distribution, or provision of temporary safe shelter). • May not include administration of medication, cleaning in areas not occupied by client. 10 hour limit/week. • 2 hour limit/week first month; 1 hour limit/week thereafter. • 1 hour limit/week. • May not be a component of DOH program.		

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
		emotional and/or social functioning.		• 4 day limit/week		
Department of Mental Health ➢ Division of Mental Retardation and Developmental	Over all programs: • 9 CSR 45-2.010 Eligibility process • Sec. 630.005 RSMo Eligibility		Over all programs: • Determined by DMRDD Regional Center to have mental retardation and/or a developmental disability	Over all programs: • Services must be identified in a person center plan • Receipt of services is limited to available DMRDD resources (except for Case Management)		
	Case Management (MOCABI eligibility process) • Sec. 633.110 RSMo MRDD Services	• Intake/screening admission • Social evaluation • Identification of service needs • Service planning • Case coordination • Case monitoring	• Determined by DMRDD Regional Center to have mental retardation and/or a developmental disability (injured before age 22).		• GR funded Community Programs • GR/FED funded Title XIX TCM • County SB-40 Boards/FED Title XIX TCM	• All persons eligible for Mental Retardation-Developmental Disabilities Regional Center services are eligible for case management (Lake court decision)
	Purchase of Services (POS) • Sec. 630.405 RSMo POS Services	• Evaluation • Therapy • Habilitation • Training • Residential habilitation			GR funded Community Programs	• Complete Standard Means Test to determine any consumer family financial responsibility for all programs.
	Community Placement	• Community residential living arrangements such as group homes, residential care centers, Individual Supported Living centers, semi-independent living, etc. • Room and board support for MRDD Waiver participants			GR funded Community Programs	
	Family Directed Support	• Family training • Family directed respite and personal assistant services • Purchased community supports and services			• GR funded Community Programs • GR/FED funded Title XIX	• Families agree to assist in meeting need and to participate in training (philosophy)

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
	Choices for Families	• Respite, Supplies, Transportation, Home Modifications, Adaptive Equipment, etc., approved by the DMRDD Regional Center			• GR funded Community Programs • Limited to $3,600 per individual	• Families may receive vouchers to obtain services from authorized providers • Families can be reimbursed by submitting receipts
	Autism	• Respite, Therapies, Home Adaptations, Behavior Intervention, etc., approved by the DMRDD Regional Center	• Determined by DMRDD Regional Center to have autism	• Monthly/daily caps on units may apply to some services	• GR funded Community Programs • GR/FED funded Title XIX	• This program has been looked to as a model for TBI. Persons with TBI would only be eligible if also have a diagnosis of autism
	ICF/MR • CFR 435.1009 Federal Developmental Disabilities definition	• 24-hour institutional care • Active treatment	• Medicaid eligible • Diagnosis of MRDD and be in need of active treatment as determined by Division of Aging	• Services must be cost effective in comparison to ICF/MR costs	GR/FED funded Title XIX ICF MR	
	MRDD Waiver • Section 1915(c) of the Social Security Act • Sec. 208.152.1.(22) Waiver Services	• Residential Hab, ISL, Day Habilitation, Supported Employment, Transportation, O.T., S.T., P.T., Behavior Therapy, Crisis Intervention, Counseling, Personal Assistant, Respite, Home Modification, and Adaptive Equipment	• Medicaid eligible • Determined by DMRDD Regional Center to require ICF/MR level of services	• Monthly/daily caps on units may apply to some services	GR/FED funded Title XIX HCBS Waiver	
• Division of Alcohol and Drug Abuse	Comprehensive Substance Treatment and Rehabilitation • Division 30 - Certification Standards Chapter 3 - Alcohol and Drug Abuse Programs • 9 CSR 30 - 3.810 thru 9 CSR 30 - 3.970 (CSTAR)	• Day Treatment • Individual and group counseling • Individual and group codependency counseling • Family Therapy • Community Support • Group Education	DSM IV criteria met for substance abuse or dependence	Must perform standards mean test for POS services	• Medicaid • General Revenue • Block Grant	Also provides specialized services for: • Adolescents • Women and Their Children • Cognitive Disabilities

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
	General Treatment Services • Division 30 - Certification Standards • 9 CSR 30-3.010 thru 9 CSR 30- 3.600 Chapter 3 - Alcohol and Drug Abuse Programs	• Detoxification • Residential • Outpatient	DSM IV criteria met for substance abuse or dependence	• Waiting list exist for residential services • Must perform standards mean test for POS services	• General Revenue • Block Grant	Missouri Rehabilitation Center/ Crossroads Center (Mount Vernon) is specifically geared to serve TBI survivors with substance abuse problems.
• Division of Comprehensive Psychiatric Services	Outpatient Services 9 CSR 30-4.100 through 9 CSR 30-4.190 Certification Standards for Outpatient Programs	• Services may include individual counseling and therapy, family therapy, medication services, crisis intervention, respite care, integrated supported employment, case management and other services as described in the Purchase of Service catalog.	Persons must have a DSM IV psychiatric diagnosis.	• Services must be documented in an Individual Treatment Plan • 80% of the funds must be used for SMI, forensic, SED, and acute psychiatric crisis • Receipt of services is limited to available CPS resources.	Over all programs: GR funded Standard Means Test to determine any consumer/family financial responsibility.	
	Supported Community Living Program (formerly Community Placement) • Statutory authority for the program exists in 630.605 • Eligibility criteria and application process defined in 9 CSR 50-2.010 and 9 CSR 50-2.510	• Services as authorized by the case manager may include housing and associated costs, personal spending, medications, and mental health treatment services. Living arrangements may include apartment living, residential care facilities, nursing facilities, group homes, residential treatment facilities and therapeutic foster homes.	Services are available to both children and adults. Children and adults must have a primary DSM IV diagnosis that is not alcohol and drug abuse or mental retardation and must meet functional criteria that has existed over a period of time.	• Medical needs that supersede psychiatric needs will result in determination of ineligibility • Receipt of services is limited to available CPS resources.	• Funds for children and adults have separate appropriations and funding cannot be shifted between appropriations. Regional appropriations are managed through the DMH 57 system.	Access to services is through the administrative agents in the Northwestern, Southwestern, and Eastern regions. For the Central and Southeast regions, contact regional staff at Fulton State Hospital and SEMO Mental Health Center respectively.
	Adult Targeted Case Management • Title XIX TCM • CPS designates providers of TCM services	• TCM is consistent with the "broker" model of case management and includes the following functions: individual assessment; service coordination and support; monitoring of service delivery and effectiveness; and documentation of activities.	• Medicaid eligible • Determined by CPS Administrative Agents to have serious mental illness and meets one of the following criteria: has been recently discharged or has had at least 2 periods of inpatient hospitalization for	• Services must be identified in an Individual Treatment Plan. • Must be 18 years old or over.	• GR/FED funded Title XIX TCM	For Adult and Children/ Youth Targeted Case Management and Community Psychiatric Rehabilitation Program, persons who meet the diagnostic/disability eligibility criteria but are not Medicaid eligible may

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
			psychiatric treatment within the previous year; or, meet the criteria for inpatient psychiatric hospitalization and will be diverted from inpatient hospitalization through use of intensive community-based treatment and service delivery; or has been conditionally released from a psychiatric facility; or is a client of the Division's Supported Community Living program.			also be eligible to receive these services through the Purchase of Service system
	Children/Youth Targeted Case Management • Title XIX TCM • CPS designates providers of TCM services	• TCM is consistent with the "broker" model of case management and includes the following functions: individual assessment; service coordination and support; monitoring of service delivery and effectiveness; and documentation of activities.	• Medicaid eligible • Determined by CPS Administrative Agents to have serious emotional disturbance and meets one of the following criteria: Children and youth from the public mental health system 6-17.9 years of age who have a DSM IV diagnosis, meet the state definition for SED and meet one of the following criteria: currently participating in a Families First or Extended Families First program; or admitted to DMH inpatient facility, DMH licensed residential program, Treatment Family Homes Program, or intensive day treatment, partial hospitalization programs; or on a waiting list for DMH funded psychiatric inpatient or residential placement; or children who are SED and are homeless.	Services must be identified in an Individual Treatment Plan.	• GR/FED funded Title XIX TCM	

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
	Community Psychiatric Rehabilitation Program • Title XIX Rehabilitation Option • 9 CSR 30-4.030 through 9 CSR 30-4.047 Certification Standards for Community Psychiatric Rehabilitation Programs	• Intake Evaluation, Crisis Intervention, Medication Administration, Psychosocial Rehabilitation (day treatment), Annual Evaluation, Community Support, Physician Consultation, and Medication Services.	• Medicaid eligible • Admission criteria includes a diagnosis of serious mental illness and disability as described in 9 CSR 30-4.042	• Services must be under the direction of a physician • Services must be identified in an Individual Treatment Plan • Certain monthly/daily billing caps.	• GR/FED funded Title XIX Rehabilitation Option	

Department of Elementary and Secondary Education,
➢ Division of Vocational Rehabilitation
	Vocational Rehabilitation Services
	• Rehabilitation Act of 1973 as amended.
	• Title I
	
	Supported Employment
	• CFR 363.6
	• Title VI, Part B
		• Vocational guidance and counseling
		• Job training (commercial/trade school, college, on-the-job)
		• Work evaluation and adjustment
		• Transportation allowance (during medical treatment/job training)
		• Equipment for work (tools, or a license, if required)
		• Assistive devised which increases the individuals ability to work
		• Interpreter services
		• Help finding a job as well as solving problems with/at job
		• Supported Employment
		  • Competitive work in integrated settings for individuals with most severe disabilities
		  • For whom competitive employ-ment has not traditionally occurred
		  • For whom competitive employ-ment has not been interrupted or intermittent
		  • Who need intensive supported employment services from VR and extended services after transition in order to perform this work
			• Persons who have a disability (physical or mental impairment)
			• People who have a disability making it difficult for them to have a job.
			• People who require work-related services because of their disability.
				Services are individually planned, depending on what a person's needs are to get a job.	Federal grant with State matching dollars	To participate, assurances have to be made that long term support is available.

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
➢ Division of Special Education	Sheltered Workshop 178.900 RSMo	An extended employment setting, with low supervisor to consumer ration. Wages are based upon piece-rate work, in a subcontract setting	Eligibility for Sheltered Workshop and Supported Employment determined to be an individual with the most significant disability, and not be capable of competitive employment in an integrated work setting	Must meet state certifications	State, other contributions and contract work	Administered by Division of Special Education, Division of Vocational Rehabilitation certifies client for sheltered workshop employment
➢ Division of Vocational Rehabilitation - Independent Living	178.651-178.658 Title VII, Chapter 1, Part B of the Rehabilitation Act of 1973	• Information and referral • Independent living skills training • Peer counseling (including cross-disability peer counseling • Individual and systems advocacy	Any individual with a severe disability	Services are limited by funding available	• GR • Federal Title VII of the Rehabilitation Act	Services promote a philosophy of independent living, including a philosophy of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence and productivity of individuals with disabilities. The program is designed to facilitate the integration and full inclusion of individuals with significant disabilities into the mainstream of American society.
➢ Division of Vocational Rehabilitation - Personal Care Assistance	• 178.669 RSMo • 5 CSR 90-7.010	• Those services required by a physically disabled person to enable him/her to perform those routine tasks necessary to enter and maintain employment or to live independently.	• Is employed or is ready for employment, or is capable of living independently with personal care assistance • Is physically disabled • Has a documented need for a minimum of 7 or maximum of 42 hours per week of personal care assistance. If more than 42 hours per week are required, substantial documentation may be used to support a request for additional time. • Has a financial need as determined by the Division	• Only serves consumers with physical disabilities • Limited number of hours (6) per day • Limited by state appropriations	GR	

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION
			according to a standard (financial) means test			
➢ Division of Vocational Rehabilitation – Disability Determinations	20CFR, Section 404.1601 and 416.1601	Determinations of Disability filed under Title II and Title XVI of the Social Security Act	Applicants filing for benefits must meet the requirements of the Social Security regulations	State agency makes the determination of disability based entirely on federal laws and regulations	100% federal (from Social Security Trust Fund Administrative Budget)	
➢ Division of Special Education	• Chapter 162 RSMo • PL 105.17	• Assist schools in providing free and appropriate public education to children and youth with disabilities. • Provide oversight for IDEA	Children with disabilities between the ages of 3 and 21	• Student must have a medical diagnosis of head injury • Student's education performance is adversely affected by deficits in acquisition, retention, and/or generalization of skills.	• GR • Federal	• Reauthorization of IDEA for 1990 added Traumatic Brain Injury and Autism as an eligibility for Special Education services. • IDEA requires report of TBI

❖ Missouri Head Injury Advisory Council was created by executive order on March 5, 1985. It was established by law to plan and make recommendations to the general assembly, governor, and other policymakers for a service delivery system, including prevention, for survivors of traumatic head injury and their families.

❖ Definitions for the Department of Mental Health are located in Chapter 630 (state authority to do programs); ADA - 631, CPS - 632, MRDD - 633.

TERMS

ADA – Alcohol and Drug Abuse
BSHCN – Bureau of Special Health Care Needs
CPS – Comprehensive Psychiatric Services
DMH – Department of Mental Health
DMS – Division of Medical Services
DOH – Department of Health
DSM IV – Diagnostic Symptoms Manual IV
DSS – Department of Social Services
EPSDT – Early Periodic Screening Diagnosis and Treatment
FCHC – Federal Community Health Centers
FQHC – Federally Qualified Health Centers
FED – Federal
GR – General Revenue
HCFA – Health Care Financing Administration
HCBS – Home Community Based Services
ICF/MR – Intermediate Care Facilities for Mentally Retarded
IDEA – Individual with Disability Education Act
ISL – Individualized Supported Living
MR/DD – Mental Retardation/Developmental Disabilities
NEMT – Non Emergency Medical Transportation
NF – Nursing Facility
O.T. – Occupational Therapy
PASARR – Pre-admission Screening and Annual Resident Review
P.T. – Physical Therapy
RHC – Rural Health Centers
SMI – Severe Mental Illness
SED – Severe Emotional Disability
S.T. – Speech Therapy
TBI – Traumatic Brain Injury
TCM – Targeted Case Management

GAPS

❖ Intermediate Care – "next step" after medical rehab and/or when client is ready to move to community independence
❖ Home and community based services
❖ Supports for community living
❖ Psychological and substance abuse services in rural areas
❖ Behavioral services for crisis management or significant behavioral problems that will lead to significant secondary conditions, i.e., entry into the correctional system or physical harm to self/other

EXISTING SERVICES THAT BECOME BARRIERS

❖ Identification of special needs of persons with TBI and implementation of specialized procedures for assessment and follow along within agencies that serve TBI, but not as their primary population, i.e., someone attending the interview process with the client
❖ Need education of public administrators/case managers
❖ Make recommendations for application process
❖ Be more consistent in naming programs across departments
❖ Work on outcomes, set benchmarks (standards)
❖ Different benefit packages for school age and 21 years old
❖ Mechanism to share information across departments, i.e., quarterly meetings or some regular interagency forum
❖ Crises Intervention Team for TBI
❖ Lack of supported employment providers in rural areas

DEPARTMENT	STATUTE / LAWS / REGULATIONS / POLICY	SERVICES OFFERED	ELIGIBILITY	LIMITATIONS	FUNDING	OTHER INFORMATION

RECOMMENDATIONS

Head Injury Advisory Council:

- Develop an educational committee to work with the Bar Association on management of TBI individuals who violate the law and those who need intervention to keep from violating the law.
- Advisory Committee to develop criteria and standards for TBI units in nursing homes

Department of Social Services, Division of Medical Services:

- Remove restrictions on Personal Care during the same hours as Comprehensive Day if medically necessary and behavior dictates.

Department of Health and the Head Injury Advisory Council:

- Assess current clients' needs, considering development of home and community based services vs. facility based.

Departments of Social Services, Mental Health and Health

- Collaborate on development of a structured neuro-behavioral unit as appropriate.
- Develop collaborative services for psychological and substance abuse in rural areas.
- Develop data system to communicate across departments.

Department of Health

- Evaluate services/benefits available to children and align them with adult benefits as appropriate.

Department of Health and Department of Social Services, Division of Medical Services

- Review and revise Interagency Agreement on Transportation for TBI.

Department of Health and Department of Elementary & Secondary Education, Division of Vocational Rehabilitation

- Reinstate or develop a supported employment committee to assure seamless services for long term follow up.

Appendix B

Traumatic Brain Injury Interagency Action Plan
September 9, 1999

RECOMMENDATION	LEAD PERSON	ACTIVITIES/PLAN
➢ Develop an educational committee to work with the Bar Association on management of TBI individuals who violate the law and those who need intervention to keep from violating the law. ➢ Advisory Committee to develop the criteria and standards for TBI units in nursing home.	Head Injury Advisory Council/Susan Vaughn	Susan Vaughn has contacted the Council member who is an attorney to check into the existence of a mental health committee under the Missouri Bar Association. Susan will also follow up with the Division of Comprehensive Psychiatric Services.
➢ Assess current clients' needs, considering development of home and community based services vs. facility based.	Department of Health and the Head Injury Advisory Council/Diane Poole	On July 23rd surveys were mailed to clients participating in the Bureau of Special Health Care Needs (BSHCN) Head Injury Program during FY99. Of 395 surveys sent, 158 responses were received (41.1%). Results are being tabulated, and a final report will follow.
➢ Collaborate on development of a structured neuro-behavioral unit as appropriate.	Departments of Social Services, Mental Health and Health/Susan Vaughn	The Head Injury Advisory Council committees on Medical and Rehabilitative Care and Life Long Community Services met August 5th to discuss recommendations for a service delivery system, including the need for developing behavior interventions and alternatives. The committee focused on the philosophy, outcomes, and the organization of the delivery process. It made a tentative recommendation that respite service for individuals in crisis be developed in order to temporarily remove an individual from a volatile situation or to provide a temporary alternative for those who are discharged from a facility due to behavior. The committee will continue to discuss these needs in upcoming meetings. Susan has information from other states regarding reimbursement for neuro-behavioral services. The committee presented its recommendations regarding service delivery at a council meeting held

		August 17 and to the providers on August 18. The committees plan to visit some providers in the upcoming weeks. The committees will meet next on September 28 to make recommendations for service categories, and possibly meet with families and individuals regarding needs.
➢ Develop collaborative services for psychological and substance abuse in rural areas.	John Solomon, Susan Vaughn, Dianne Tackett and Diane Poole	Met with the DMH Executive Team to bring this issue to the attention of Dorn Schuffman, Director, Division of Comprehensive Psychiatric Services, Michael Couty, Director, Division of Alcohol and Drug Abuse, and Dr. Roy Wilson, Director, DMH. Met with Susan Vaughn and Dr. Laura Schopp, Rusk Rehabilitation Center, to explore the possibility of using telemedicine to connect the Department's service system with the expertise at Rusk Rehabilitation and other specialty providers. Arranged for a presentation by Dr. Schopp to the DMH Executive Team to discuss the potential of telemedicine implementation within the Department. Discussed with Fordyce Mitchel, Deputy Division Director-Federal Programs, DMH, the potential of developing a TBI Waiver. This is a Division of Medical Services issue and would require major policy decisions within their agency. Mr. Gary Ball, Management Analyst Specialist, could provide us some expertise in this area.
➢ Develop data system to communicate across departments.	Ron Cates	Discussions are occurring.
➢ Evaluate services/benefits available to children and align them with adult benefits as appropriate.	Diane Poole	The Bureau of Special Health Care Needs is in the preliminary stages of planning how to address adolescence with TBI within the Children's Program.

➢ Review and revise Interagency Agreement on Transportation for TBI.	Diane Poole	A draft of wording changes has been submitted to the Bureau Chief, Bureau of Special Health Care Needs and will be submitted to Division of Medical Services by October 1.
➢ Reinstate or develop a supported employment committee to assure seamless services for long term follow up.	Division of Voc. Rehabilitation/ Greg Solum	The Missouri Division of Vocational Rehabilitation will take the lead in developing a state task force early this fall in order to reassess the current status of supported employment services for persons with head injury. The task force shall consist of representatives from the Missouri Division of Head Injury, Missouri Division of Vocational Rehabilitation and Supported Employment Service Providers who have in the past served persons with head injury. The initial plan would be to get all parties together and discuss current and future services. From this meeting it is hopeful that a format can be laid out to begin enhancing the service delivery system for this population. In addition, MDVR will provide, as well as other vocational data, past and present, as to the number of individuals being served with head injury in supported employment.

Appendix C
Staff of Interim Committee on Head Injury

Joseph A. Deering, Ph.D.,.....House Research
Birdie Duff .....Assistant to Representative Paula J. Carter

Endnotes

1. Missouri. Office of Administration. Missouri Head Injury Advisory Council. *Overview of Traumatic Brain Injury*, p. 4; pp. 11-16.

2.U.S. Department of Health and Human Services. National Institutes of Health. *Consensus Development Conference Statement: Rehabilitation of Persons with a Traumatic Brain Injury, October 26-28, 1998, pp. 2-3.*

3.Ibid., pp. 4-6.

4.Ibid., p. 8. The National Institutes of Health indicates that the figures underestimate the economic burden to families and society because they do not include lost earnings, costs to social service systems and the lost earnings of family members who care for persons with a traumatic brain injury.

5.Missouri. Department of Health, Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report, 1996, Table 3-A, p. 17.* This number includes the number of non-admitted deaths and individuals admitted to Missouri acute care and rehabilitation hospitals.

6.Missouri. Department of Health, Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report, 1996, Figures 3, 5,and 6, pp. 4-5. The actual number of traumatic brain injuries for individuals aged 15-24 years in 1996 was 982; for individuals aged 65 and over was 872.* The number of head injuries experienced by White Americans in Missouri in 1996 was 3,609 persons and the number of African Americans and other persons of color who experienced a head injury in 1996 was 650 persons. For the number of head injury occurring in an etiological category, see Tables 3-B, 3-C, 3-D, 3-E and 3-F, pp. 18-22.

7.Missouri. Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program,* October 15, 1999. The 380 persons eligible to receive rehabilitation services for fiscal year 1999 included persons who received services; persons who did not receive services and persons who received services through another agency. The remaining 155 persons were individuals who received service coordination only. In 1998, the total number of persons enrolled in the Department of Health was 379 persons of which 228 persons were eligible to receive rehabilitation services.

8.Missouri. Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. *Traumatic Brain Injury Consumers for the State of Missouri: A Statistical Report FY 1999.* This figure includes the successful and non-successful closures as well as those receiving enrolled at the end of the fiscal year.

9.Missouri. Department of Elementary and Secondary Education, Division of Special Education. *Information on Traumatic Brain Injury, December 1, 1998.* Information for year ending December 1, 1997 was provided by telephone by Ms. Lina Browner, Division of Special Education on November 12, 1999.

10.Missouri. Department of Mental Health. Division of Mental Retardation and Developmental Disabilities. *Information on Traumatic Brain Injury for the State of Missouri, Fiscal Year 1997.* Information for 1998 and 1999 were not available at the time of this report.

11. Missouri. Department of Social Services, Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury, Fiscal Years 1998 and 1999.* The information was obtained through a telephone conversation with Ms. Diane Tackett, of the Division of Medical Services on November 17, 1999.

12.Missouri. Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program,* October 15, 1999.

13. Ibid.

14.Ibid.

15.Ibid.

16.Missouri. Department of Mental Health, Office of the Director of the Division of Mental Retardation and Developmental Disabilities. *Demographic and Financial Data for Persons with a Traumatic Brain Injury. Fiscal Year 1997.*

17. Missouri. Department of Social Services, Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury, Fiscal Years 1998 and 1999.* Expenditure information was obtained through a telephone conversation with Ms. Diane Tackett, of the Division of Medical Services on November 17, 1999.

18.Missouri. Department of Elementary and Secondary Education, Division of Vocational Rehabilitation. *Financial Information on Basic Support Services and Supported Employment Services for Persons with a Disability, 1998-1998.* The figures for basic support services were based on 839 persons and 826 persons for 1998 and 1999. The figures for supported employment were based on 46 persons and 55 persons for 1998 and 1999.

19.Ibid.

20. See Appendix A for a complete listing of state services for persons with a traumatic brain injury which was compiled by the Missouri Department of Health, Bureau of Special Health Care Needs, October, 1999.

21.Missouri. General Assembly. 1985. *Joint Interim Committee on Head Injury: Report and Recommendations*, p. B-1.

22.U.S. Government. House of Representatives. *Traumatic Brain Injury Act of 1996, Public Law 104-652.*

23.U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, September, 1999,* p. 2.

24.Ibid., p. 3.

25.Missouri. Department of Health. Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October 1999.*

26.Ibid.

27.Ibid.

28. U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, September, 1999,* p. 11.

29. The Missouri Head Injury Advisory Council meeting was held September 27, 1999.

30. Missouri. Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

31. Missouri. Department of Health. *Traumatic Brain Injury Program Matrix*, October 1999.

32. *State of Missouri, Revised Statutes, 1998, section 630.005 (13).* Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

33. Ibid., *Solomon.*

34. Missouri, Department of Health, Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October 1999.* Section 1915 (c) of the Social Security Act does allow a state agency (i.e., the Department of Social Services) to apply for a *Traumatic Brain Injury, Home and Community Based Waiver.* See the federal statutes, 42 U.S.C., Section 6001 (8), 42 C.F.R., Section 435.1009 and 42 U.S.C.A., Section 1396 n (c).

35.Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities. Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September 1999.

36.Missouri General Assembly, 1991. House Bill 218 and Senate Bill 125 & 341.

37.Missouri. Department of Health, Bureau of Special Health Care Needs. *Traumatic Brain Injury Program Matrix, October, 1999.*

38. U.S. Department of Health and Human Services, Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program, FY 1999,* p. 11.

39.Ibid., pp. 1-4.

40.The Interagency Committee consisted of representatives of the Missouri Head Injury Advisory Council, the Department of Social Services, the Department of Mental Health and the Department of Elementary and Secondary Education, Division of Vocational Rehabilitation.

41. U.S. Department of Health and Human Services, Health Resources and Services Administration, *Application Guide for Traumatic Brain Injury, State Demonstration Grant Program,* September, 1999, p. 3.

42.U.S. Government, National Institutes of Health. *Report of the Consensus Development Conference Statement for Rehabilitation of Persons with a Traumatic Brain Injury. October 26-28, 1998,* p. 12.

43.Ibid., p. 14.

44.Missouri, Department of Health. *Traumatic Brain Injury Program Matrix, October 1999; Interagency Action Plan, September, 1999.*

45. U.S. Government, General Accounting Office. *Traumatic Brain Injury: Programs Supporting Long Term Services in Selected States, February, 1998, pp. 6-9.* For a discussion of the Home and Community Based Waiver, see U.S.C.A. Section 1396 n(c).

46.Missouri. Department of Health. *News Release: Department Will Seek Supplemental Funding For Head Injury Services, 21 July 1999;* Department of Health, Bureau of Special Health Care Needs. *The Adult Head Injury Program,* October 15, 1999; Department of Health, Bureau of Special Health Care Needs, Letter from A. Diane Poole to Traumatic Brain Injury Service Providers, 25 June, 1999.

47.Ibid.

48.This provision contains state statutes pertaining to the Head and Spinal Cord Injury Registry.

49.Missouri. Department of Health. Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report,* 1996, p. 1.

Bibliography

Missouri - Executive

Missouri. Department of Elementary and Secondary Education. Division of Special Education. *Information on Traumatic Brain Injury*. Jefferson City, December 1998.

Missouri. Department of Elementary and Secondary Education. Division of Vocational Rehabilitation. *Financial Information on Basic Support Services and Supported Employment Services for Persons with a Disability, 1998-1999*. Jefferson City, 1999.

_____. *Traumatic Brain Injury Consumers for the State of Missouri: A Statistical Report*. Jefferson City, 1999.

Missouri. Department of Health. Bureau of Special Health Care Needs. *The Adult Head Injury Program*. Jefferson City, 1999.

_____. *Interagency Action Plan*. Jefferson City, September, 1999.

_____. *Letter from A. Diane Poole to Traumatic Brain Injury Services Providers*. Jefferson City, 25 June, 1999.

_____. *Traumatic Brain Injury Program Matrix*. Jefferson City, October, 1999.

Missouri. Department of Health. Center for Health Information Management and Epidemiology. *Missouri Head and Spinal Injury Registry Report*. Jefferson City, 1996.

Missouri. Department of Health. *News Release: Department Will Seek Supplemental Funding for Head Injury Services*. Jefferson City, 21 July 1999.

Missouri. Department of Mental Health. Division of Mental Retardation and Developmental Disabilities. *Information on Traumatic Brain Injury for the State of Missouri*. Jefferson City, 1997.

Missouri. Department of Mental Health. Office of the Director of Mental Retardation and Developmental Disabilities. *Demographic and Financial Data for Persons with a Traumatic Brain Injury*. Jefferson City, 1997.

_____. *Letter from Mr. John Solomon to Representative Paula J. Carter, 29 September, 1999.*

Missouri. Office of Administration. Head Injury Advisory Council. *Overview of Traumatic Brain Injury*. Jefferson City, 1994.

Missouri. Department of Social Services. Division of Medical Services. *Statistics on Persons with a Traumatic Brain Injury*. Jefferson City, 1998.

_____. *Statistics on Persons with a Traumatic Brain Injury*. Jefferson City, 1999.

Missouri - Legislative

Missouri. General Assembly. *An Act to Create a Division of Injury Prevention, Head Injury Rehabilitation and Local Health Services*. 86th General Assembly, H.B. 218 (28 August, 1991).

_____. *An Act Relating to Driving While Intoxicated*. 86th General Assembly, S.B. 125 & 341 (28 August, 1991).

Missouri. General Assembly. Joint Interim Committee on Head Injury. *Joint Interim Committee on Head Injury: A Report and Recommendations*. 1985.

Missouri - Other

Missouri. *Revised Statutes, 1994.*
_____. *1999 Supplement.*

U.S. Government - Executive

U.S. General Accounting Office. *Traumatic Brain Injury: Program Supporting Long Term Services in Selected States*. Washington, D.C., 1998.

U.S. Department of Health and Human Services. Health Resources and Services Administration. *Application Guidance for Traumatic Brain Injury State Demonstration Grant Program*. Washington, D.C., 1999.

U.S. Department of Health and Human Services. National Institutes of Health. *Consensus Development Conference Statement: Rehabilitation of Persons with a Traumatic Brain Injury*. Washington, D.C., 1998.

U.S. Government - Legislative

U.S. Congress. House of Representatives. *Traumatic Brain Injury Act of 1996*, 104th Congress, *Public Law 104-652*.

U.S. Government - Other

Definitions Relating to Institutional Status. 42 Code of Federal Regulations, Section 435.1009.

U.S. Department of Health and Human Services. Health Care Financing Administration. Home and Community Based Waiver. 42 U.S. Code (Annotated), Section 1396 n (c).

Programs for Persons with Disabilities. U.S. Code, Section 6001 (8).